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Effects of School Re-Entry Programs on School-Age Individuals with Chronic Illnesses Post-Hospitalization

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Effects of School Re-Entry Programs on School-Age Individuals with Chronic Illnesses Post-Hospitalization

by

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Abstract

Effects of School Re-Entry Programs on School-Age Individuals with Chronic Illnesses Post-Hospitalization

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Children with chronic illnesses are at risk for a variety of negative outcomes. They have lower rates of academic achievement, less school engagement, fewer peer connections, and poorer psychological outcomes (Gottfried, 2014; Martinez & Ercikan, 2009; Kaffenberger, 2006). School re-entry after a hospitalization provides a unique opportunity for interventions that improve functioning in students with chronic illnesses. Currently, there is no established evidence-based standard of care around hospital to school transitions. The proposed study aims to determine quantitatively which type of school re-entry program has the most significant impact on school, social, and psychological outcomes for chronically ill children and adolescents in order to determine the optimal school re-entry program model. This proposed study uses a randomized control design with a sample of hospitalized patients at Dell Children's Medical Center to determine the impact of 3 different school re-entry programs (presentations to school

staff, presentations to healthy peers, and educational liaison programs) on school, social, and psychological functioning over time for chronically ill children and adolescents. Variables will be a mixture of caregiver and child report measures and school outcomes. A repeated measures multiple analysis of variance (MANOVA) will be used to investigate the impact of treatment condition on academic, social, and psychological outcomes over time. This study would determine the benefit of school re-entry liaison programs and school presentations within a general hospital setting. It would also contribute to the establishment of an evidenced-based intervention to address some of the psychological, social, and academic challenges that youth with chronic illnesses face after hospitalizations

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Introduction

In the United States it is estimated that between 15 to 18 million children will experience a chronic illness (Van Cleave, Gortmaker, & Perrin, 2010; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). Children with chronic illnesses are at risk for a variety of negative outcomes. They have lower rates of academic achievement above and beyond the cognitive impacts of their diseases (Martinez & Ercikan, 2009; Maslow, Haydon, McRee, & Halpern, 2012). They also on average miss five times more days of school than healthy students (McDougall et al., 2004). School absences lead to missed instruction time, less engagement in the classroom, and decreased connection with peers (Gottfried, 2014). Increased school absences also relate to lower self-esteem, higher levels of helplessness, and long-term social problems (Boles, 2017; Kaffenberger, 2006). Transitions back to school after hospitalizations are critical times for students with chronic illnesses. Students often experience anxiety about school return due to a range of concerns such as fears about falling behind in school work and worries about peer reactions to changes in appearance (Dockett, 2004; Herrmann, Thurber, Miles, & Gilbert, 2011; Sexson & Madan-Swain, 1995). Additionally, school personnel often report that they feel unprepared to meet the needs of chronically ill students who return to their classroom after hospitalizations (Tresman, Brown, Fraser, Skinner, & Bailey, 2016; Wilson et al., 2014).

Models for school re-entry programs have been developed to address the needs of students with chronic illnesses as they return to school. These programs strive to target the school, hospital and/or family systems in order to improve a variety of outcomes. A 2012 meta-analysis of school re-entry programs for children with chronic illnesses found that only three

types of school re-entry programs had been compared to a control group (Canter & Roberts, 2012). These three types of school re-entry programs were presentations to school staff, presentations to healthy peers, and educational liaison programs. They are also the types of programs most commonly described in the literature. Research on school re-entry programs is limited. A 2016 meta-analysis of school re-entry programs for children with cancer, the most researched population for school re-entry, stated that the majority of studies have low sample sizes and lack control groups (Helms et al., 2016). There is even less support for the effectiveness of these interventions in non-diagnosis specific samples of children and adolescents with chronic illnesses. This is a deficit in the literature because the majority of medical centers serve a range of diagnoses. These problems with the research have delayed the creation of an evidence-based standard of care for the return to school of students with chronic illnesses (Schilling & Getch, 2018). The current study aims to address these issues. The study's goal is to determine quantitatively which type of school re-entry program has the most significant impact on school, social, and psychological outcomes for chronically ill children and adolescents in order to determine the optimal school re-entry program model.

Integrative Analysis and Interpretation

Chronic Illness in Pediatric Populations

In the United States it is estimated that between 15 to 18 million children (1 out of 4 children) will experience a chronic illness that may impact school functioning (Van Cleave et al., 2010; van der Lee et al., 2007). A chronic illness is "a medically diagnosed ailment with a duration of 6 months or longer, which shows little change or slow progression" (Williams, 1997, p. 312) and does not spontaneously clear up (Stanton, Revenson, & Tennen, 2007). Due to advances in medicine, many children with chronic illnesses are able to return to school relatively quickly. However, 5.9 million children in the United States experience overnight hospital stays annually (Witt, Weis, & Elixhauser, 2014) and students with chronic illnesses miss five times more days of school than their healthy peers (McDougall et al., 2004). After leaving the hospital and returning to school, chronically ill children may encounter a variety of factors that interfere with school functioning including academic difficulties, social isolation, and psychological challenges. They are at increased risk for internalizing and externalizing problems post-hospitalization compared to children with acute illnesses (Levy, Kronenberger, & Carter, 2008). Students with chronic illnesses have poorer school experiences and outcomes than students without chronic illnesses (Canter & Roberts, 2012; Lum et al., 2017). School re-entry after a hospitalization provides a unique opportunity to initiate interventions that improve school functioning. Currently, there is no established evidence-based standard of care around hospital to school transition for children and adolescents with chronic illnesses (Thompson et al., 2015).

Chronic Illness and Academic Challenges

Chronic illness presents a variety of challenges to academic achievement. Physiological changes may impact academic performance. Certain chronic illnesses affect cognition and hinder a student's ability to function in school. For example, cancer survivors reported that attention problems and pain were significant barriers to school reintegration (Vetsch et al., 2017). Other chronic medical conditions have been found to impact cognitive functioning such as cardiac and respiratory issues (Wray, Long, Radley-Smith, & Yacoub, 2001). Children with chronic Lyme disease were found to have cognitive deficits in attention and memory after controlling for depression, anxiety, and fatigue (Tager et al., 2001) and children with sickle cell disease were also found to have disease related cognitive deficits (Steen et al., 2005). However, these physiological differences do not fully account for the discrepancies in school functioning between healthy and chronically ill students.

Chronic illnesses impact academic achievement beyond their effect on cognitive abilities. Most children and adolescents with chronic illnesses have average cognitive scores but lower scores on achievement tests (Sexson & Madan-Swain, 1995). A longitudinal study in Canada reported that after controlling for educational disabilities, adolescents with chronic illnesses had lower scores on mathematics exams than healthy peers (Martinez & Ercikan, 2009). Parent education and overall quality of life were found to contribute to academic achievement in students with sickle cell disease after controlling for cognitive ability (Smith, Patterson, Szabo, Tarazi, & Barakat, 2013). Fewer young adults with chronic illness graduate college than their healthy peers (Maslow et al., 2012).

Chronic illness affects academic achievement due to a variety of factors. Specific types of chronic illnesses, such as diabetes, sickle cell anemia, and epilepsy, have been found to affect

academic achievement (Taras & Potts-Datema, 2005). A meta-analysis on school outcomes in chronically ill children and adolescents found that disease severity, stronger side effects of treatment, and lower SES were linked with worse school experiences and outcomes in medically ill students (Lum et al., 2017). Additionally, the type of educational setting where a student is placed during treatment can impact school performance. Although high achieving students before a cancer diagnosis performed equally well academically in a homebound setting, a community school setting, or a hospital school setting, low achieving students did significantly better academically in a hospital school or a community school relative to homebound services. (Searle, Askins, & Bleyer, 2003).

School accommodations and chronic illness.

Despite changes in cognitive and physical functioning, many children and adolescents do not receive appropriate special education services or disability accommodations. A lack of appropriate services and accommodation can impede individuals' academic progress and ability to navigate school demands. Bhat and colleagues (2005) reported that although children with brain tumors and their parents noticed decreases in their ability to function at school, only 30% of students received special education services. Additionally, despite the cognitive impact of traumatic brain injuries (TBI) 60% of children with TBIs do not receive appropriate school-related services because of the delayed effects of these injuries and a failure by school personnel to monitor students' symptoms and progress after their return to school (Grandinette, 2014). Adolescents with chronic kidney disease who did not have an individualized education plan (IEP) or a 504 plan for school had significantly more emergency department visits, inpatient admissions, and inpatient days than individuals with formalized school accommodations

(Javalkar, Fenton, Cohen, & Ferris, 2014). Despite these benefits only half of adolescents with chronic kidney disease had an IEP or 504 plan (Javalkar et al., 2014). Proper school supports through IEPs or 504 plans could improve children with chronic illnesses' ability to attend school, function academically, and regulate their medical symptoms.

School absences and academic functioning.

Elevated school absences are a key academic challenge that youth with chronic illnesses face. Children with chronic illnesses miss around 16 days of school a year, which is significantly greater than their healthy peers who on average miss around 3 days a year (McDougall et al., 2004). School absences lead to missed instruction time and less engagement in the classroom. Chronic school absences are related to reduced educational engagement, social engagement, and math and reading scores (Gottfried, 2014). Increased school absences in students with chronic illnesses are related to a variety of factors including diagnosis, disease-related stress, adjustment to the diagnosis and treatment, child and family response to illness, and parent education (Boles, 2017; Sexson & Madan-Swain, 1995; Shaw & McCabe, 2008). Bladder control issues and taking medications at least twice a day are also negatively related to school attendance (Richardson, Weiss, & Halbach, 2018). The variety of factors related to school absences suggests that interventions that target family and child factors separate from physical symptoms may directly impact school attendance. Improving attendance is important to long-term educational outcomes. Individuals with cancer who continue to receive school instruction during their illness or attend school during treatment were more successful at school during remission and had normal school trajectories (Fottland, 2000). School absences can also be a burden to parents who must properly document medical absences to avoid legal issues (Boles, 2017). Attendance impacts a student's

ability to connect with the school and to learn new skills. Exclusion from these important opportunities can impair development in chronically ill students.

Grade retention and chronic illness.

Individuals with chronic illness are also at risk for grade retention due to excessive absences and impediments to the completion of school assignments. For example, it is estimated that 23–54% of children with sickle cell disease are retained for at least one grade, which is significantly larger than the national average (5–10%) in the United States (Ladd, Valrie, & Walcott, 2014). A 2017 meta-review of literature reviews on school experiences for children and adolescents with serious chronic illnesses identified three reviews, that found higher rates of grade retention in pediatric illness populations (Lum et al., 2017). Grade retentions has a significant effect on students. Chronically ill students who are retained have higher anxiety about academic performance and peer relationships than chronically ill students who are not (Bessel, 2001). Grade retention has also been linked to poorer academic achievement, higher dropout rates, and lower attendance (Jimerson, 2001; Ladd et al., 2014). Students with chronic illness are already at elevated risk for these negative outcomes. Grade retention has the potential to exacerbate existing academic challenges.

School personnel and students with chronic illnesses.

An additional academic challenge that school-age students with chronic illnesses face is a lack of support from school staff and teachers. School personnel report feeling poorly prepared to meet the needs of chronically ill children (Canter & Roberts, 2012). Teachers report that it is difficult to assess the impact of a medical condition on a student's behavioral and emotional well-being (Wilson, Gaskell, & Murray, 2014). They also expressed concern about what to

expect from chronically ill children's schoolwork and how to judge their capacity to complete schoolwork (Kliebenstein & Broome, 2000; Wilson et al., 2014). Lack of preparation and training extends beyond teachers. Kaffenberger (2006) reported that 71% of elementary school counselors and 83% of secondary school counselors felt unprepared to provide support with transitions back to school for students with chronic illnesses. School personnel often want more information and more time to adequately prepare for a child's re-entry into school (Tresman, Brown, Fraser, Skinner, & Bailey, 2016; Wilson et al., 2014). School staff's lack of understanding and training with students who have chronic illnesses prevents these students from receiving appropriate instruction.

School personnel have a major impact on the school re-entry process and students' academic outcomes. In individuals with cancer, students' relationships with their teachers was found to have the greatest impact on students' perceptions of the school re-entry process (Yi, Kim, Hong, & Akter, 2016). A qualitative study of Australian adolescents with diverse medical diagnoses reported that students' concerns around medical absences related to support from and interactions with teachers (Wilkie, 2014). Chronically ill children and adolescents' self-reported ratings of school connectedness before the age 18 was a main predictor of college graduation (Maslow et al., 2012). School connectedness was not as important for healthy students' higher education outcomes. Additionally, a sample of adolescents with cancer reported that both prejudice and a lack of teacher understanding were major problems in school re-entry (Yi et al., 2016). A meta-analysis of school experiences and outcomes in youth with chronic illness found teacher attitudes and the student's engagement with the school to be the most important modifiable factors that impact school outcomes (Lum et al., 2017).

Individuals with chronic illnesses face a variety of academic challenges. Many of these challenges such as lack of appropriate school accommodations, high rates of school absences, and unprepared school personnel, are distinct from illness-related cognitive effects. If these modifiable and environmental barriers are addressed early in a student's return to school many of the negative academic consequences related to chronic illness in pediatric populations could be reduced. These system level barriers illustrate the challenges that students face beyond the physical symptoms.

Student perceptions of school.

Despite these academic challenges many students with chronic illnesses continue to value school performance. Studies have found that the majority of medically ill children and adolescents state that educational performance is as important to them or more important post-diagnosis and that being perceived as a capable student is highly valued during treatment (Boles et al., 2017; Vetsch et al., 2017). Teenagers with cancer reported that they continued to consider school important after their diagnosis and that they had a strong desire to continue to participate in normative educational experiences (Pini, Gardner, & Hugh-Jones, 2018). Secondary students with complex medical illnesses reported both that education was important to their life goals and that they felt continuously disconnected from school (Ferguson & Walker, 2014). Children's beliefs about their ability to succeed academically are related to their beliefs about their ability to cope with treatment (Crossland, 2002). Academic performance was found to be related to general self-esteem in children with cancer which suggests that success in school can impact the child's global self-concept (Fottland, 2000). Based on Erikson's theory of psychosocial development it has been hypothesized that school provides an environment in which children can

address the crisis of industry versus inferiority because it allows them to gain and master new skills (Boles et al., 2017). The removal of students with chronic illnesses from school or a failure to provide adequate supports prevents these individuals from developing a sense of mastery and accomplishment that could have long lasting psychological effects.

Chronic Illness and Social Challenges

Chronic illness can also affect social relationships with peers, which has a strong impact on school experiences. Emerson and colleagues (2016) found that school functioning strongly related to social relationships. Adolescents with chronic illnesses reported that peer and teacher relationships had the greatest impact on school re-entry (Yi et al., 2016). There is a significant positive relation between maintenance of peer relationships, educational supports, and a successful integration into school in students with chronic illnesses (Pini, Gardner, & Hugh-Jones, 2013). A randomized control study found that middle and elementary school students with cancer who received social skills training upon re-entry into school reported greater improvements in overall school competence compared to a control group (Varni, Katz, Colegrove, & Dolgin, 1993). In addition, lower parent ratings of social functioning predicted increased school absences in students with chronic illnesses (Emerson et al., 2016). These findings indicate that social functioning should be considered in the design and assessment of school re-entry programs.

The social relationships fostered in school impact the psychological functioning of individuals with chronic illnesses. Many children rely on school to make and interact with friends and an interruption to this process can have far reaching effects. Students enrolled in schools in their community or hospital have significantly greater social competence, emotional

stability, and quality of life than students who are socially isolated through homebound services or one-on-one tutoring (Bessell, 2001). Additionally, perceived social support from peers is more highly related to positive psychological adjustment in children with chronic illnesses than perceived social support from teachers or parents (Varni et al., 1993). Increased restrictions around spending time with friends and attending school due to chronic pain has a direct effect on depressive symptoms in adolescents (Walters & Williamson, 1999). These types of findings suggest that peer relationships are an important factor in the psychological well-being of children and adolescents with chronic illnesses and that continued access to peers leads to better outcomes.

School absences and social functioning.

The frequent absences associated with chronic illnesses impact a child's ability to participate in the social aspects of school. Increased school absences are related to decreased self-esteem and long-term social problems (Boles, 2017). There is evidence that chronic illness and extended absences from school can impact individuals' social skills. Vance and Eiser (2001) found that children with cancer, who were frequently absent from school, were more socially isolated than their healthy peers in the classroom. During transitions back to school after treatment, adolescents with cancer reported a sense of loss around the school social activities that they missed due to their illness (Pini et al., 2018). Increased absences from school in chronically ill individuals are related to higher levels of helplessness and sadness (Kaffenberger, 2006). Poor social functioning is an unintended cost of excessive school absences for students with chronic illnesses.

Bullying and chronic illness.

Negative interactions with peers create significant challenges for individuals with chronic illnesses. Students with chronic illnesses face higher levels of bullying than their healthy peers. One study reported that children and adolescents with cancer were three times more likely to be bullied than healthy peers (Lähteenmäki, Huostila, Hinkka, & Salmi, 2002). A sample of medically ill adolescents reported that bullying was a major problem upon returning to school (Yi et al., 2016). Parents of chronically ill children also reported that peers were a source of bullying and lacked empathy and understanding of their child's condition (Janin, Ellis, Lum, Wakefield, & Fardell, 2018). Bullying is related to different negative outcomes such as school refusal and truancy (Havik, Bru, & Ertesvåg, 2015). Students with chronic illnesses are more likely to engage in school refusal than health peers (Shiu, 2001). Bullying in school may contribute to these increased rates of school refusal. Additionally, one study found that students who are concerned about their peers' reactions to changes in their appearance as a result of their illness often opt for homebound services that cause social isolation and delay school reintegration (Searle et al., 2003). Peer relationships are important components of a child's school experience. A student's social competence should be considered and monitored during school re-entry in order to ensure optimal outcomes for children and adolescents with chronic illnesses.

Chronic Illness and Psychological Challenges

Individuals with chronic illnesses are at greater risk for psychosocial symptoms (Barlow & Ellard, 2006). Students with certain chronic illnesses have increased rates of depression and anxiety (Gorin & McAuliffe, 2008). Children with chronic Lyme disease were found to have significantly higher rates of suicidal thoughts than healthy controls (Tager et al., 2001). A

comparison of pediatric patients with 10 different chronic conditions including diabetes, gastrointestinal conditions, cardiac conditions, asthma, cancer, and rheumatologic conditions to healthy peers found that psychosocial health and psychological functioning was lower for children with chronic illnesses (Varni, Limbers, & Burwinkle, 2007b).

Children and adolescents with chronic illnesses encounter psychological challenges that relate to school re-entry and impact school outcomes. School experiences can impact the psychological well-being of children and adolescents with chronic illnesses. Students often experience anxiety about school re-entry. Australian students who returned to school after excessive absences due to a chronic illness reported feeling worried about the type of information individuals at the school knew about their illness and that they looked different from their peers (Dockett, 2004). Adolescents with cancer reported feeling lonely, sad, and isolated upon school re-entry (Yi et al., 2016). They also reported anxiety due to changes in their physical appearance due to treatment.

Theoretical Foundations of School Re-Entry Models

The theoretical origins of school re-entry models stem from Bronfonbrenner's systems theory that hypothesizes that to understand human development one must consider the ecological systems a person inhabits (Bronfenbrenner, 1994). School re-entry models aim to improve the development of children with chronic illnesses by targeting the different systems in which they exist. Current school re-entry models assume that effective school re-entry programs connect the school, hospital, and family systems (Shields, Heron, Rubenstein, Rubenstein, & Katz, 1995). Shields and colleagues (1995) built on this concept to create an eco-triadic model of educational consultation for patients with pediatric cancer. This model was designed to impact all three

systems by increasing communication between classmates and the patient during hospital stays, and by using an educational consultant with knowledge of medical treatments, diagnoses, educational law, teaching methodology, classroom interventions, peer reintegration, and the impact of cancer on children and families. Shield's eco-triadic model was an extension of the original triadic model proposed by Tharp and Wetzel (1969) that targets child behavior in multiple settings. Tharp and Wetzel's model was designed for healthy children with problem behaviors. Shield's eco-triadic model of educational consultation has expanded beyond pediatric cancer and has been applied to children with chronic illnesses in general (Worchel-Prevatt et al., 1998). Sexson and Madan-Swain (1993) used this eco-triadic model to design a comprehensive theoretical model for the ideal school re-entry program for students with chronic illnesses. Their theoretical program followed four main guidelines to improve the family, school, and medical systems: (1) prepare the child and family by providing educational/special education law resources and tutoring for the child, (2) prepare school personnel through results of an in-hospital psychological and academic evaluation of the child, (3) prepare the child's class through a presentation by the medical team, (4) continue to follow-up after the child's return to school. The authors stressed that the program be individualized to each child due to within diversity of chronically ill pediatric populations.

School re-entry programs use this theoretical basis to achieve their overarching goals: to improve attendance and academic achievement, to foster peer relationships, to strengthen teacher support, and to decrease the burden for families (Nabors & Lehmkuhl, 2004). Nabors and Lehmkuhl (2004) note that the child's mental health and social functioning are growing concerns for school re-entry interventions. Common challenges to school re-entry programs include a lack

of adequate time to devote to the child's re-entry, lack of knowledge about professional roles and responsibilities regarding the re-entry, and a school culture that is perceived as unsupportive (Poursandiou, Garner, & Watson, 2008). School staff and parents have noted additional specific areas of concern about children's re-entry into school including the logistics of the school re-entry process, communicating the child's illness to the school, monitoring of the child's health in school, school personnel's ability to handle unexpected health problems, and school expectations for the child with a chronic illness (Kliebenstein & Broome, 2000). These practical aims and concerns have been the basis of a variety of types of school re-entry programs.

Types of School Re-Entry Models

Based on these concepts, three main types of school re-entry programs have emerged in the literature. A 2012 meta-analysis of school re-entry programs for chronically ill children reported that only three types of school re-entry programs have been compared to a control group (Canter & Roberts, 2012) including (1) presentations to school staff, (2) presentations to healthy peers, and (3) educational liaison programs. These three programs are the primary forms of school re-entry services available in the United States. Prevatt, Heffer, and Lowe (2000) described the implementation of these three types of school re-entry programs for patients with pediatric cancer. The school staff presentation was suggested to last one or two days and cover basic information on cancer, attitudes about cancer patients, and the impact of working with students with cancer (Prevatt et al., 2000). The goal of these workshops was to increase the school personnel's knowledge and confidence in working with students with cancer. The second form of intervention was a peer education program designed to increase peer interactions and decrease peers' misconceptions of cancer (Prevatt et al., 2000). The third level of intervention was the

provision of a liaison to prepare the sick child to return school, to assess the goals and needs of the parent, and to create collaborative communication between school, hospital, and family in a highly individualized way (Prevatt et al., 2000). Although a 2016 meta-analysis of school re-entry programs for children with cancer reported significant increases in academic achievement and lower levels of depression following school re-entry programs, these results are not generalizable due to the diversity of types of interventions included in the analysis as well as methodological problems with many of the studies (i.e. lack a control group and small sample sizes) (Helms et al., 2016).

School Re-Entry Models-School Staff Focused

Pediatric cancer.

A variety of school re-entry models that target teacher knowledge and skills have been studied. The results of these programs have been mixed. An initial study on faculty-focused re-entry programs evaluated a workshop that provided information about childhood cancer to public and private school teachers (Baskin, Saylor, Furey, Finch Jr, & Carek, 1983). After the workshop teachers had higher scores on knowledge about pediatric cancer and more positive attitudes towards children with cancer. This study was later replicated with another workshop on pediatric cancer for school personnel that again found that participants reported significant increases in their knowledge of medical and psychological aspects of pediatric cancer and less worry about children with cancer at school (Pallmeyer et al., 1986). Beyond face-to-face presentations, Dubowy and colleagues (2006) evaluated a 2 to 4-hour computer-based training program on childhood cancer's effects on students and intervention strategies for teachers. Teachers made significant gains in their knowledge about cancer and their self-reported application of skills after the training. A larger meta-analysis found that school re-entry programs that focused on

school personnel increased knowledge about medical and psychosocial aspects of cancer, improved teacher's attitudes towards children with cancer, and enhanced their confidence in their ability to manage challenges associated with teaching a student with cancer (Thompson et al., 2015).

Currently, no study has looked at whether these changes in knowledge or attitudes result in better outcomes for children with cancer. Additionally, prior studies have found that there is no significant relation between the number of services to facilitate school re-entry for children with cancer and the number of continuing education workshops either the nurse or school personnel have attended (Moore, Kaffenberger, Goldberg, Oh, & Hudspeth, 2009). This finding calls into question the benefit of school personnel focused presentations on academic, social, or emotional outcomes for children with chronic illnesses. More research is required to determine the effectiveness of these types of programs.

Other chronic illnesses.

There is little research on school staff focused interventions in chronically ill populations beyond pediatric cancer. The only published work in individuals without cancer looked at a presentation to school faculty and staff prior to a child with burn injury's return to school (McCartney, Fowler, James, & Warner, 2018). The information in these presentations were rated as useful by school staff. However, no information on the impact of the interventions on child outcomes was reported. Further exploration is required to determine the extent that these types of interventions improve medically ill children's school re-reentry.

School Re-Entry Models-Peer Focused

Pediatric cancer.

There has been limited research on school re-entry programs involving healthy peers. However, education of a child with cancer's classmates is still considered an important component of effective school re-entry programs (Prevatt et al., 2000). An intervention that looked at a workshop for classmates of children with cancer found that after a workshop healthy classmates demonstrated greater knowledge of cancer and an increased desire to interact with the student with cancer (Benner & Marlow, 1991). However, there was no significant change in classmates' level of concern for the child with cancer. This study did not provide any evidence that this change in knowledge and desire to interact impacted observable interactions between the classmates or the social functioning of children who have cancer. Helms and colleagues (2016) reported that increased knowledge among classmates was related to less fear and a more positive attitude towards the student with cancer. There may also be gender differences, that impact the results of peer focused school re-entry programs. Teachers reported that peer presentations had a greater impact on social acceptance, peer interactions, and classmates' emotional affect for female students as compared to male students with cancer (Katz, Varm, Rubenstein, Blew, & Hubert, 1992). However, further research on the effectiveness of peer intervention programs in general needs to be completed before effectiveness of these types of school re-entry interventions can be confirmed.

Other chronic illnesses.

Recent publications continue to advocate for peer-focused school re-entry programs that involve educational workshops for healthy peers about the disorder (Nowakowska, 2018). The only existing research on peer focused school re-entry programs in populations other than cancer was completed with children and adolescents with burn injuries. Results show mixed support for

the effectiveness of peer interventions. One study found no significant differences in child adjustment with or without peer presentations for individuals returning to school after hospitalization for a burn injury (Blakeney et al., 1995). However, the study had a small sample size. Another study found that patients who received individualized videos from their classmates and school visits during recovery after a burn injury had no significant differences in socialization with peers, support from peers and staff, enjoyment of school, and teasing compared to a group who received no peer-focused re-entry program (Rosenberg et al., 2007). An intervention for youth with burn injures that involved placing a stuffed bear in the patient's seat with an envelope to collect letters and messages from the patient's classmates was reported to be useful by all patients involved in the program (Dunlap, Kagan, Arnold, & Gottschlich, 2013). Medical personnel also reported that they felt the program helped children's school re-entry. No findings on the children's social functioning once they returned to school were reported. Another study that evaluated a school re-entry program that provided teachers with a packet of information on burn injuries and centered around an informational presentation to healthy classmates, found that after the introduction of this program the length of time between hospital discharge and return to school decreased 62.3% for pediatric patients with burn injuries (Arshad et al., 2015). More research needs to be conducted to determine if peer-focused school re-entry programs impact children with chronic illnesses transitions back to school beyond improving self-reported knowledge and attitudes of their healthy peers. Additionally, there needs to be a greater examination of these re-entry programs with more types of chronic illnesses. Due to the impact that peers have on children's school experience and functioning (Emerson et al.,

2016; Pini et al., 2013; Yi et al., 2016) it is important to determine which types of interventions can improve social functioning for students with chronic illnesses as they return to school.

School Re-Entry Models-Liaison Focused

Pediatric cancer.

The greatest amount of research on school re-entry programs involves a liaison focused model. However, few explicit models of these programs for students with cancer exist and they vary by whether the liaison-consultation process is set in the school or medical facility (Harris, 2009). A program is considered to have a liaison component if it involves an individual embedded in one system (school or medical facility) who facilitates communication between the school, family, and medical team and is available to provide consultation to individuals within all three systems. Prevatt, Heffer, and Lowe (2000) stated that for school re-entry programs for children with cancer to be effective, an individual must be identified who will coordinate school reintegration services and that consultation with both medical team and school personnel must occur. Liaison focused models address both of these components because the liaison can serve as a consultant for the family and medical team as well as a liaison between the different systems.

A large portion of existing research on school re-entry programs is qualitative and evaluates the program based on semi-structured interviews with the family or medical staff. Parents of children with cancer have reported improved advocacy skills in the school setting and less concerns related to peer teasing after participating in a liaison focused school re-entry program (Thompson et al., 2015). However, the program had no impact on parental concerns regarding their child's safety. Another qualitative study on a school re-entry program for children with brain tumors found that parents reported the program improved their child's learning and social achievements (Bruce, Newcombe, & Chapman, 2012). Additionally, teachers found that the

school liaison program improved their ability to implement educational curriculum tailored to the child's needs. In another assessment of a school re-entry program for children with cancer, teachers said that knowledge and hospital-school communication were important for the child's long-term success in school (Tresman et al., 2016). Communication and close collaboration between medical staff, school personnel, and the family are critical components to meet children's educational, social, and behavioral goals upon re-entry into school for children with cancer (Bruce et al., 2012; Thompson et al., 2015; Tresman et al., 2016).

One of the few quantitative studies on liaison-focused school re-entry programs for children with cancer had parents rate the acceptability and utility of a school re-entry program with a liaison component. Both parents and children rated the program positively (Katz et al., 1992). Another study randomized children who were newly diagnosed with cancer into a school reintegration program with a liaison component or a school reintegration program with a liaison and social skills training component (Varni et al., 1993). The group that received social skill training reported higher perceived classmate and teacher social support at the 9-month follow-up compared to school reintegration group alone. This study does not provide a control condition where a school reintegration program without a liaison component was studied. Further quantitative research is required to evaluate the effectiveness of a liaison component in school re-entry programs and to determine its benefits above and beyond treatment as usual.

Other chronic illnesses.

Worchel-Prevatt (1998) expanded existing models of school re-entry for individuals with pediatric cancer to individuals with any chronic illness. This paper proposed use of a hospital-based liaison to coordinate the patients return and to connect the different ecological systems

(family, school, medical, peers). This conceptual model was designed to increase regular school attendance in order to improve the child's academic, psychological, and social outcomes. The school re-entry team was responsible for: (1) developing hospital-based goals and plans, (2) referring patients to psychological services if coping style was thought to impact school attendance or performance, (3) communicating with teachers and school staff, (4) referring to social workers if lack of financial or physical resources impeded school re-entry, (5) teaching families basic education law and their rights, and (6) helping set-up services within school that were based on medical staff recommendations. Koenning and colleagues (1995) reported that one third of the hospital's school-age populations used these services. However, it did not provide any quantitative information on its impact. Researchers have also proposed a hospital-based consultation-liaison model for school re-entry programs for pediatric cardiac transplant patients where a liaison works with the school to assist in academic planning and to consult on academic, emotional, and behavioral supports prior to school re-entry and after their return to school (Weil, Rodgers, & Rubovits, 2006). This paper is purely theoretical and does not provide information on the impact of these programs on academic, psychological, or social functioning.

A qualitative study on perceptions of parents of seriously ill children, school personnel, and healthcare providers on existing school re-entry resources found that communication and collaboration between school and medical establishments are variable and mostly inadequate (Vanclooster, Benoot, Bilsen, Peremans, & Jansen, 2018). Parents and teachers specifically said they would like to know more about the medical impact of the child's disease. All stakeholder groups reported a need for a liaison who could connect the family, education, and healthcare systems. They reported a desire to have a liaison to monitor the child's school experiences and

to ensure parents, school staff, and medical providers have access to relevant information. A literature review on school re-entry programs for children with burn injuries using a thematic analysis of qualitative findings found that good communication established early and continued throughout hospitalization is a crucial component to facilitate the integration (Pan et al., 2018). However, the researchers found no studies that examined the quantitative impact of liaison services that foster communication for students with burn injuries' return to school. Another study found that parents of children with complex medical conditions who participated in a school re-entry program with hospital-based liaison services reported improved advocacy skills and less school related concerns after working with the program (Botcheva, Hill, Kane, Grites, & Huffman, 2004). These studies suggest that parents of children with chronic illnesses report a desire for school re-entry programs with a liaison component that addresses communication barriers. However, there is limited research on the effectiveness of these types of programs on child outcomes.

A 2012 meta-analysis of school re-entry programs for individuals with chronic illnesses found one published study in non-cancer populations that compared these liaison-focused school re-entry programs to a control group (Canter & Roberts, 2012). The study was a randomized control trial for individuals with sickle cell anemia (Koontz, Short, Kalinyak, & Noll, 2004). It compared 10 individuals who received no school re-entry services with 14 individuals who received school integrated services with a liaison component as well as a peer in-service training and a faculty in-service training. Teachers, children with sickle cell anemia, and healthy peers in the school re-entry program group had greater increases in knowledge on a general knowledge questionnaire than teachers, children with sickle cell anemia, and peers in the control group.

There were no differences in parent knowledge. Children in the school re-entry condition also had fewer absences and more positive self-concept than children in the control. However, the school re-entry program described in this study involves interventions with peers and faculty through in-services as well as a liaison. It is difficult to determine the impact of different components on student outcomes. Additionally, the study had a small sample size. As a consequence, it is unclear if the study is generalizable. A 2018 randomized control trial that compared a standardized liaison-based hospital to school transition program for students with TBI to treatment as usual, found no significant differences in special education eligibility status, support services, academic accommodations, executive functioning or psychological symptoms (Glang, Todis, Ettel, Wade, & Yeates, 2018). However, the authors suggested that these findings may be due to problems with dose of the treatment. Despite the wide use of liaison services in hospital-based school re-entry programs, more research is necessary to determine their effectiveness for pediatric patients with diagnoses beyond cancer.

Limitations in the Literature

There are many limitations within the existing literature. Current research on school outcomes for children and adolescents with chronic illnesses in general is narrowly focused and the majority of research has been completed with individuals with cancer, HIV/AIDS, and sickle cell anemia (Canter & Roberts, 2012). Research on school re-entry interventions is even more limited. The majority of studies involved individuals with pediatric cancer. In the United States approximately, 171 people per million are diagnosed with pediatric cancer (Siegel et al., 2014). This is a small percentage of the number of children and adolescents who experience chronic illnesses and return to school. Pediatric cancer has unique characteristics. For example,

individuals with cancer have higher rates of school absences than other individuals with chronic health conditions (Vance & Eiser, 2001). It is important to differentiate between research with pediatric cancer populations and research performed with other chronic illness populations. A successful school re-entry program for this population may not be effective for children and adolescents with other chronic illnesses. The expansion of research to individuals with other diagnoses is needed to determine which interventions are effective in other medical populations.

Current research does not align with the reality of the majority of school re-entry programs in applied settings. Most studies look at a single disease population. However, the creation and implementation of separate school re-entry programs for each diagnosis is unrealistic for the majority of healthcare centers that treat a wide range of chronic illnesses. Research that assesses the impact of general chronic illness school re-entry programs is needed. School re-entry needs may also be less related to the specific diagnosis and more connected to other factors such as visibility of condition, degree of life-threatening, impact on sensory or motor abilities, demanding/intrusiveness of care, or effect on cognitive functioning (Barlow & Ellard, 2006; Lum et al., 2017; Pan et al., 2018; Richardson et al., 2018). Research on non-diagnosis specific school re-entry programs could assess the relationship between these factors and successful school re-entry and is also more representative of the format of school re-entry programs in large medical settings.

Another major limitation with the literature is the lack of quantitative research on school re-entry. Currently, qualitative studies make up the majority of research. There is a lack of information on how these programs impact naturalistic outcomes, such as school attendance or school accommodations. There are few randomized control trials of school re-entry programs. A

2012 meta-analysis found only four studies in non-cancer populations that compared an experimental group to a control group to asses school re-entry programs (Canter & Roberts, 2012). These studies focused on changes in global self-worth or peer/teacher knowledge and attitudes. Few studies looked at specific school outcomes or social functioning.

Additionally, although presentations to peers and faculty members are often mentioned as important components of school re-entry programs, there is limited information on their impact on student outcomes. Research has focused on changes in peer or teacher knowledge or attitudes toward children with chronic illnesses. Information on whether these presentations impact the child's school, social, or psychological functioning is extremely limited. Current findings around whether they improve student's re-entries are mixed. More work is needed to clarify to what extent these types of programs directly benefit children and adolescents with chronic illnesses.

Helms and colleagues (2016) summarize many of the methodological issues with current school re-entry literature in a meta-analysis of school re-entry programs for children with cancer, the most researched population. They stated the majority of studies have low sample sizes, lack control groups, and use diverse interventions. These problems are magnified in other disease populations. They prevent the field from determining the optimal type of re-entry program and has delayed the creation of an evidence-based standard of care with specific components (Schilling & Getch, 2018).

Proposed Research Study

Purpose and Rationale

The purpose of the current study is to quantitatively determine which type of school re-entry program (treatment as usual, school presentations, and educational liaison) has the greatest impact on school, social, and psychological outcomes for chronically ill children and adolescents.

Primary research question 1. To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact school outcomes in chronically ill children and adolescents post-hospitalization over time?

Research question 1a. To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact school absences over time in chronically ill children and adolescents post-hospitalization?

Hypothesis 1a. The hospital liaison group will have a significantly greater decrease in school absences post-hospitalization than the school presentation group and the treatment as usual group at 20 school days and the 12 months timepoint. The school presentation group will have a significantly greater decrease in school absences post-hospitalization than the treatment as usual group at the 20 school days timepoint and the 12-month timepoint.

Rationale: There is no research comparing all three types of school re-entry programs. The hospital liaison service has the potential to impact the largest number of factors related to school absences in chronically ill children and adolescents, such as parent perceptions of child's functioning, parental overprotectiveness, parental stress, and unclear messages from medical teams (Emerson et al., 2016; Sexson & Madan-Swain, 1995). The liaison group works directly

with parents to address concerns around their child's capacity to attend school and to improve communication between the medical team, family, and school. The school presentation group does not address these barriers. However, interventions aimed at improving teacher and peer knowledge can lead to a modest reduction in school absences compared to a treatment as usual group (Koontz et al., 2004). It is expected that this finding will be recreated in the present study.

Research Question 1b. To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact the creation or revision of IEPs or 504 plans over time in chronically ill children and adolescents post-hospitalization?

Hypothesis 1b. The hospital liaison group will have a significantly higher incidence of new or revised IEPs or 504 plans post-hospitalization than the school presentation group and the treatment as usual group at 20 school days and 12 months. The school presentation group will have a significantly higher incidence of new or revised IEPs or 504 plans post-hospitalization than the treatment as usual group at 20 school days and 12 months .

Rationale: The focus of the hospital liaison is to foster collaboration between the school, family, and medical team to ensure the child receives the appropriate support at school. School re-entry liaisons have been found to increase communication between the school, family, and medical team and to improve the advocacy skills of families (Botcheva et al., 2004; Pan et al., 2018). This increased communication and advocacy is anticipated to increase the number of new or revised IEPs and 504 plans over time compared to the school presentation and treatment as usual group. Disease specific trainings to school staff have been previously found to increase knowledge about the condition and strategies to address it in school settings (Dubowy et al.,

2006; Thompson et al., 2015). It is predicted that increased knowledge will lead to the creation of more formalized school accommodations (IEPs/504 plans) because it will highlight the need for specific accommodations due to the chronic illness to the school staff and increase the likelihood a child will be referred for an evaluation.

Research Question 1c. To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact grade retention in chronically ill children and adolescents post-hospitalization?

Hypothesis 1c. The hospital liaison group will have significantly lower rates of grade retention post-hospitalization over a 12-month period than the school presentation group and the treatment as usual. The school presentation group and the treatment as usual group will not significantly differ in grade retention rates.

Rationale: Despite evidence to suggest that grade retention has a major impact on chronically ill children and adolescents' perceptions of their academic competence and peer relationships (Bessell, 2001), no studies have looked at the impact of school re-entry programs on grade retention. Unexplained absences and inadequate accommodations can contribute to grade retention for chronically ill students. The liaison intervention improves communication between the school and the medical staff to address these problems. The school presentations intervention does not directly intervene with the structural issues, such as standardized assessments or attendance requirements, that often lead to grade retention and is not expected to differ the frequency of grade retention from treatment as usual.

Primary Research Question 2. To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact psychological and social outcomes over time in chronically ill children and adolescents post-hospitalization?

Research Question 2a. To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact social competence over time in chronically ill children and adolescents post-hospitalization?

Hypothesis 2a. The school presentation group will have a significantly greater increase in social competence as measured by the social competence scale on the Home and Community Social Behavior Scale than the liaison group and the treatment as usual group post-hospitalization at 20 school days and 12 months. The liaison group will have a significantly greater increase in social competence as measured by the social competence scale on the Home and Community Social Behavior Scale than treatment as usual group post-hospitalization at 20 school days and 12 months.

Rationale: Social functioning are often impacted by chronic illnesses and are a predictor of long-term academic and psychological outcomes (Bessell, 2001). School presentations to peers of chronically ill youth can increase knowledge and positive attitudes toward the student and decrease fear (Canter & Roberts, 2012; Helms et al., 2016). The presentations were also found to increase behavioral intentions to interact with chronically ill students (Holtz & Tessman, 2007). These behavioral intentions may result in more peer interactions, which would result in improved social competence for the patient. The liaison program does not directly target peers and is expected to have lower impact on parent-rated social competence than the school presentation group. However, increased school attendance is related to less disruption in peer

relationships (Pini et al., 2013); the liaison program is expected to have greater effects on social competence than treatment as usual.

Research Question 2b. To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact self-reported psychosocial functioning over time in chronically ill children and adolescents post-hospitalization?

Hypothesis 2b. The hospital liaison group will have significantly greater increases in psychosocial functioning at 20 school days and 12 months as measured by the Psychosocial Health Summary score of the PedsQL child version than the school presentation group and the treatment as usual group post-hospitalization. The school presentation group will have significantly greater increases in psychosocial functioning at 20 school days and 12 months as measured by the Psychosocial Health Summary score of the PEDSQL child version than the treatment as usual group post-hospitalization.

Rationale: School placement following treatment has been shown to significantly affect psychological outcomes in children with cancer (Bessell, 2001). However, no study has quantitatively examined which type of school re-entry program has the greatest impact on psychosocial functioning for the general population of children and adolescents with chronic illnesses. Chronically ill students often report psychosocial stress related to school re-entry, such as feeling a sense of loss, and a difficult school transition, which relates to poorer social competence and less emotional stability (Bessell, 2001; Yi et al., 2016). It is expected that a designated liaison to facilitate a smoother re-entry into school will improve the psychosocial functioning related to school re-entry. It is estimated that the school presentation re-entry

program would be able to impact social difficulties but have less of an impact on the other school re-entry stressors, which are addressed by the liaison program. Both programs are anticipated to have a greater impact than treatment as usual, which does not address any psychosocial stressors related to school re-entry.

Research Question 2c. To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact parent ratings of their child's psychosocial functioning over time in chronically ill children and adolescents post-hospitalization?

Hypothesis 2c. The hospital liaison group will have significantly greater increases in psychosocial functioning at 20 school days and 12 months as measured by the Psychosocial Health Summary score on the PEDSQL parent version than the school presentation group and the treatment as usual group post-hospitalization. The school presentation group and the treatment as usual group will not significantly differ in changes in psychosocial functioning at either 20 school days and 12 months as measured by the Psychosocial Health Summary score of the PEDSQL parent version.

Rationale: Parent-reported child psychosocial functioning differs in its relations with school outcomes compared to child self-reports (Emerson et al., 2016). Additionally, prior research has found low consistency between parent report and child report (Cremeens, Eiser, & Blades, 2006), which is why it is hypothesized that school re-entry programs will affect parent-rated quality of life differently than self-reports. The liaison program works directly with parents to assist with the child's school re-entry. It also emphasizes the family's resources and strengths, which would have a greater impact on the parent's perception of their child's psychosocial

functioning than the school presentation or treatment as usual groups, which do not directly intervene with parents. Additionally, the liaison group facilitates communication between the school, family, and medical team. This enhanced communication may improve the parent's ability to differentiate between the physical and social/emotional impact of the chronic illness, which impacts ratings of their child's psychosocial functioning. The school presentation program does not intervene with parents and is anticipated to have a negligible impact on parent ratings of psychosocial functioning.

Methods

Participants

Participants will be at least 159 patients recruited from Dell Children's Medical Center (DCMC). An *a-priori* power analysis using G*Power indicated that recruiting 159 participants would provide a probability of 0.8 to detect a medium standardized effect (β) of 0.25 follows existing conventions (Cohen, 1988; Miles & Shelvin, 2001). Hospital personnel will refer patients to the study who are hospitalized at DCMC for at least 48 hours and are expected to transition back to school within a month. Participants will be recruited at the time of referral. Patients are only eligible for the study if they have been diagnosed with a chronic disease such as diabetes, lupus, Crohn's, cystic fibrosis, or sickle cell anemia. Individuals with an acute injury or a life expectancy of less than one year will be excluded from the study. Individuals must return to school within 20 school days from baseline to participate. They also must have at least 20 school days left in the school year. Individuals enrolled in a school, where a prior participant received the school presentations intervention will be excluded. Individuals with cancer will also be excluded because the DCMC's Children's Blood and Cancer Center has a specific school reintegration service that is markedly different from treatment as usual in the other inpatient units. Participants must be enrolled in kindergarten to twelfth grade.

Measures & Outcome Variables

Demographics.

Demographic forms will be collected from each parent. The form will assess gender, age, ethnicity/race, family income, parental education, and information about child's medical condition including type of chronic illness, history of psychological/psychiatric services, and

educational information including school name, school type (private, public, homeschool), goals related to school, existence of IEP/504, and grade.

School absences.

Each participant's number of school absences will be collected from his or her school at baseline, 20 school days after baseline and at 12 months after baseline. Absences for the 12-months prior to baseline will be collected at baseline. Absences will be analyzed as a proportion of total possible days of school. The researchers will also track the number of excused absences compared to unexcused absences. For individuals enrolled in homebound services refusal to meet with the homebound teacher on a scheduled day will be coded as a school absence.

IEP or 504 plans.

IEP is a written plan, that describes a child's special education service plan. It is created by the family and the school and provides individualized special education and related services to the child. IEPs are provided under the Individuals with Disability Education Act (IDEA). To qualify for an IEP, chronically ill children must have a condition that impacts their ability to learn in school. An evaluation for an IEP may be initiated by the school or family. A 504 plan is an individualized plan for a child with disabilities' accommodations to access learning in a general education setting. It is provided under Section 504 of the Americans with Disabilities Act. Anyone with a physical or mental impairment that substantially hinders a major life activity is eligible for a 504 plan. Researchers will collect the participants' IEP or 504 status upon entry to the study. The creation of a new IEP or 504 plan or revision of a pre-existing IEP or 504 plan during the 12-month period of the study will be collected from the school upon completion of the study. IEPs and 504 plans will be examined in combination as a categorical variable.

Grade retention.

Grade retention refers to the educational practice where students must repeat a grade level because they failed to meet grade level standards (Jones & Waguespack, 2011). This study will examine if participants advance to the subsequent grade level at the conclusion of the school year within the 12-month study timeframe. Grade retention data will be collected from participants' official school records at the 12-month timepoint. Students will be considered grade retained if they are listed in the same grade as baseline after the 12 months.

The Home and Community Social Behavior Scales.

The Home and Community Social Behavior Scales (HCSBS) is a rating scale for parents and caregivers that assesses youth between the ages of 5 to 18 on social competence (positive prosocial behaviors) and antisocial problem behaviors (Merrell, 2002c). It was normed on 1,500 cases and stratified by gender and race/ethnicity on the 2000 U.S. census (Merrell, 2002c). The HCSBS has 64 items which use a 5-pt rating scale ranging from never to frequently. It consists of 2 scales, social competence and antisocial problem behaviors. Social competence consists of the subscales of peer relations and self-management/compliance. The antisocial problem behaviors scale consists of the subscales Defiant/Disruptive and Antisocial/Aggressive. The rating scales generate standardized scores for both scales and provide levels of social functioning (High Functioning, Average, At-Risk, High Risk). The HCSBS has high internal consistency for both scales (.96-.98) (Merrell & Caldarella, 1999). It also has convergent validity with the Social Skills Rating System, the Conners Parent Rating Scale-Revised-Short Form, the Child Behavior Checklist, the Behavior Assessment System for Children, and the ADHD Symptoms Rating Scale, (Merrell & Boelter, 2001; Merrell, Streeter, Boelter, Caldarella, & Gentry, 2001). It has

shown discriminant validity through its ability to differentiate between at-risk and typical youth (Merrell & Caldarella, 1999), and individuals with learning disabilities, behavioral disorders, and the general population (Lund & Merrell, 2001). The measure has also demonstrated that it is a sensitive tool to assess treatment outcomes (Snyder, Kymissis, & Kessler, 1999). The HCSBS has also been used with pediatric medical populations (Wade, Carey, & Wolfe, 2006; Wade, Wolfe, Brown, & Pestian, 2005).

The Pediatric Quality of Life Inventory.

The Pediatric Quality of Life Inventory (PedsQL) is a brief measure designed to assess health-related quality of life in individuals between 2-18 years old (Varni, Seid, & Rode, 1999). The current study will use the PedsQL 4.0 Generic Core Scales, which are designed to be administered across diagnoses. The PedsQL 4.0 Generic Core Scales have self-report and parent-report forms and consist of 23 items (Varni, Burwinkle, Seid, & Skarr, 2003). It has been translated into English, Spanish, Korean, Vietnamese, and Chinese. Specific child self-report forms are designed for youth ages 5 to 7, 8 to 12, and 13 to 18. The PedsQL generates 3 composite scores, Total Scale Score, Physical Health Summary Score, Psychosocial Health Summary Score. This study will examine the Psychosocial Health Summary Score, which consists of the subscales examining psychological, social, and school functioning. The Psychosocial Health Summary Scale has good internal consistency for both parent report (α= .86) and child self-report (α= .83) (Varni, Seid, & Kurtin, 2001). The measure was found to have moderate test-retest reliability for both parent and child raters at the item level and high test-retest reliability at the scale level as calculated with Spearman's Rho and ICC (Petersen, Hägglöf, Stenlund, & Bergström, 2009). Construct validity was demonstrated using the known-

groups method. Specifically, the PedsQL can differentiate between healthy individuals and individuals with chronic or acute illnesses . Scores on the PedsQL also relate to days sick in bed, days needing care, indicators of morbidity, and illness burden (Varni et al., 2003, 2001). Prior research has found low consistency between parent report and youth report (ICC = 0.02 -.23), which is expected for reporters with different roles (Cremeens et al., 2006). The PedsQL 4.0 Generic Core Scales has been validated on a wide range of racial and ethnic groups (Varni, Limbers, & Burwinkle, 2007a).

Procedures

Research will be performed at DCMC and University of Texas at Austin. Participants will be referred to the study by hospital staff as soon as a patient is stable and school re-entry is estimated to be within a month. This study uses a convenience sampling method instead of a random sampling method. The random sampling method is not feasible because the researchers only have access to patients from DCMC. However, the PI will analyze demographic data to ensure it is representative of the general population of chronically ill children and adolescents in Central Texas. After a patient and their parent/caregiver have consented to participate, the research staff will administer baseline measures to both the child and the parent/caregiver. The child will complete the PedsQL. The parent will complete a demographics questionnaire, the PedsQL, and HCSBS. The existence of an IEP or 504 plan and number of school absences in the prior 12 months will be collected from the child's school. Upon completion of the baseline measures, individuals will be randomized into one of three conditions: treatment as usual, school presentations, or liaison services. The experimental conditions are described below. Participants

will be stratified into these treatment groups based on school level (elementary, middle, and high school) to prevent between group differences.

Upon entrance to the study, all participants and their caregivers will be informed that the study includes 3 time points, baseline, 20 school day follow-up and 12-month follow-up. At baseline, caregivers and participants will complete selected measures and intake information, including their demographic information and the surveys. At baseline, participants will complete the PedsQL. The caregiver will complete the PedsQL and the HCSBS. Patients and their caregivers will complete the same measures at 20 school day follow-up, and 12-month follow-up. They will be able to complete the measures electronically via RedCap or to answer questionnaires in spoken interviews in person or over the phone. All measures will be available in Spanish and English. School absences from date of the randomization until the 12-month follow-up will be collected from schools. Dates for the creation or revision of IEPs or 504 plans over the prior 12 months will also be collected from the school.

Experimental conditions.

Treatment as usual.

In the treatment as usual group, patients will receive the standard procedures provided in their inpatient units. This may vary slightly between units within the hospital. Treatment as usual at DCMC consists of either a social worker who provides the families with referrals to outside organizations who will assist with school issues, or a child life specialist, who sets up homebound services for the family as they leave the hospital. Social work and child life services stop when the child leaves the hospital.

School presentation.

In the school presentation group, a research team member will complete two presentations, one to the participant's classmates and one to the school faculty. Both school presentations must take place within a week of the participant's re-entry. The presentations will last 1-hr and include a 45-minute formal presentation and 15 minutes for audience questions. The presentation will be presented using digital slides and be provided by a member of the research staff. The faculty presentation will be designed to give a brief overview of the child's diagnosis, explain the medical and physical needs of the child, and provide guidance on how to teach individuals with chronic disease. All faculty members who teach the child will be invited to the presentation. However, homeroom teachers' attendance will be prioritized when the presentation is scheduled. Peer presentations will be designed to provide an age-appropriate overview of the patient's diagnosis and to address common misunderstandings about the diagnosis. Presentations will be diagnosis specific and may be reused for children with the same diagnosis. New presentations will be designed for children with different diagnoses. Faculty members and classmates will have 15 minutes to ask questions at the end of the presentation. However, they will not be able to contact the presenter with questions at the end of the 15 minutes. Participants in this condition who opt out of one or both of the presentations, will still be included in data analysis study.

Educational liaison.

Participants in the liaison services group will be provided with a Dell Children's educational liaison, who will facilitate communication between medical staff, school staff, and the family in an attempt to improve the patient's supports at school. Educational liaisons must have a bachelor's degree. They will be trained in special education law and the Americans with

Disabilities Act by the research team. Educational liaisons will follow a standard procedure of first identifying the child and family's strengths, resources, and educational needs. They will assess the need for provisional supports such as homebound services or online instruction. Next, the liaison will contact the family, school, and medical team to design a plan that incorporates the child and family's strengths and the academic and emotional supports the child will need upon school re-entry. The liaison will also determine if a 504 plan or IEP needs to be created or changed. Finally, the liaison will work with the family and the school to develop a system to monitor the child's academic and social progress. Throughout the process the liaison will aim to foster communication and collaboration between the family, medical team, and school. Liaison services will be individualized based on the child's level of need. The family, school, and medical team will have access to the liaison for the entire 12-month period.

Analyses and Expected Results

This study uses a randomized control design with a convenience sample of patients at DCMC to determine the impact of different school re-entry programs on school, social, and psychological functioning over time. Variables will be a mixture of caregiver and child report measures and school outcomes (i.e. grade retention, IEP/504 plans, attendance). Data will be analyzed using SPSS 25 (IBM Corporation, 2017). Descriptive statistics (means and standard deviations) will be reported for all measures in tables.

Multiple Analysis of Variance.

A repeated measures multiple analysis of variance (MANOVA) will be used to investigate the impact of treatment condition on school attendance, social competence, and psychosocial functioning (parent report and child report) over time. A 3 (treatment group) x 4 (outcome variable) X 2 (time) MANOVA will be used in order to evaluate multiple continuous dependent variables across two or more groups over time (p. 778, Warner, 2013). A model of the repeated measures ANOVA is illustrated in Figure B. There should be no systematic group differences due to the randomization process. Additionally, participants will be stratified into treatment groups based on school level (elementary, middle, or high school) to account for variability related to school level. Before the MANOVA analysis, the basic assumptions of absence of sphericity, absence of multicollinearity, and multivariate normality of the data will be tested. Sphericity will be assessed using Mauchly's Test of Sphericity. Multicollinearity will be assessed in a correlation matrix among dependent variables. Multivariate normality will be assessed by plotting the distribution of scores respectively. An intent to treat analysis will also be used. In intent to treat analysis, every participant who is randomized is analyzed in their

randomized treatment group regardless of other factors, which take place after randomizations such as noncompliance, protocol deviations, and withdrawal (Gupta, 2011). This analysis will be done to prevent overoptimistic estimates due to the removal of noncompliers and protocol deviations, which happen in applied settings. Effect size will be calculated and reported using partial η^2, which will produce a more conservative estimate and is recommend with a MANOVA (Tabachnick & Fidell, 2007). The significant group differences and significant group x time interactions will be further examined through post-hoc analyses.

If the repeated measures MANOVA is significant, four repeated measures analysis of variance (ANOVA) will be completed for each outcome variable (school absences, HCSB Social Competence Scale, PedsQL parent report, PedsQL child report). If the four ANOVAs are significant, a large number of post hoc tests would then be used to determine specific group effects and group x time interactions. To address the large number of post hoc tests, Tukey's Honest Significance Difference test (HSD) will used for post-hoc tests. The large number of analyses leads to an increase in family wise type 1 error because it inflates the chances of a significant result. Tukey's HSD will be used to account for this inflation and to limit the family wise type 1 error. Tukey's HSD is a moderately conservative and can compare all possible comparisons of means (Warner, 2013, p. 244).

Research question 1a: To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact school absences over time in chronically ill children and adolescents post-hospitalization?

A 3 (treatment group) x 3 (time) ANOVA with repeated measures on number of school absences will be performed. There is expected to be a significant main effect of treatment group.

Either the Greenhouse-Geisser or Hyunh Feldt adjusted F test will be used when interpreting effects involving the within-subjects of factor of time and will be reported with adjusted degrees of freedom rounded to the nearest whole number. There is expected to be a significant main effect of time. Both main effects are expected to be dependent upon the other, which will be indicated by the significant interaction between treatment group and time. Effect sizes will be calculated and reported using partial η^2. For post-hoc tests, using Tukey's HSD it is expected that there will be a will be a significantly greater decrease in proportion of school absences in the educational liaison group than the school presentations group or the treatment as usual group over time. It is also anticipated that the school presentations group will a significantly greater decrease in proportion of school absences than the treatment as usual group over time.

Research Question 2a: To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact social competence in chronically ill children and adolescents post-hospitalization over time?

A 3 (treatment group) x 3 (time) ANOVA with repeated measures on HCSBS Social Competence scores will be performed. There is expected to be a significant main effect of treatment group. Either the Greenhouse-Geisser or Hyunh Feldt adjusted F test will be used when interpreting effects involving the within-subjects of factor of time and will be reported with adjusted degrees of freedom rounded to the nearest whole number. There is expected to be a significant main effect of time. Both main effects are expected to be dependent upon the other, which will be indicated by the significant interaction between treatment group and time. Effect sizes will be calculated and reported using partial η^2. For post-hoc tests, using Tukey's HSD is also expected that HCSBS Social Competence scores will have a significantly greater increase in

the school presentations group than the education liaison group and the treatment as usual group over time. It is also predicted that HCSBS Social Competence scores will have a significantly greater increase in the educational liaison group than the treatment as usual group over time.

Research Question 2b: To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact self-reported psychosocial functioning in chronically ill youth over time post-hospitalization?

A 3 (treatment group) x 3 (time) ANOVA with repeated measures on adjustment the child-reported Psychosocial Health Summary score on the PedsQL will be performed. There is expected to be a significant main effect of treatment group. Either the Greenhouse-Geisser or Hyunh Feldt adjusted F test will be used when interpreting effects involving the within-subjects of factor of time and will be reported with adjusted degrees of freedom rounded to the nearest whole number. There is expected to be a significant main effect of time. Both main effects are expected to be dependent upon the other, which will be indicated by the significant interaction between treatment group and time. Effect sizes will be calculated and reported using partial η^2. For post hoc tests with Tukey's HSD it is anticipated that there will be a significantly greater increase in the child-reported Psychosocial Health Summary score on the PedsQL in the educational liaison group compared to the school presentations group and the treatment as usual group over time. Additionally, there will be a significantly greater increase in the Psychosocial Health Summary score on child-reported PedsQL for the school presentations group than the treatment as usual group over time.

Research Question 2c: To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact parent ratings of

their child's psychosocial functioning over time in chronically ill children and adolescents post-hospitalization?

A 3 (treatment group) x 3 (time) ANOVA with repeated measures on adjustment the parent-reported Psychosocial Health Summary score on the PedsQL will be performed. There is expected to be a significant main effect of treatment group. Either the Greenhouse-Geisser or Hyunh Feldt adjusted F test will be used when interpreting effects involving the within-subjects of factor of time and will be reported with adjusted degrees of freedom rounded to the nearest whole number. There is expected to be a significant main effect of time. Both main effects are expected to be dependent upon the other, which will be indicated by the significant interaction between treatment group and time. Effect sizes will be calculated and reported using partial η^2. Using Tukey's HSD post hoc t-tests are expected to find that a significantly greater increase in parent-reported Psychosocial Health Summary score on the PedsQL for liaison group than the school presentations group and the treatment as usual group over time. There is expected to be no difference in parent-reported Psychosocial Health Summary score on the PedsQL for school presentations group and the treatment as usual group over time Overall, these findings would indicate that the educational liaison intervention has greatest impact on child social, psychological, and academic outcomes for children with a chronic illness over one year following a hospitalization.

Chi Square Tests of Independence

Research Question 1b: To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact the creation or

revision of IEPs or 504 plans over time in chronically ill children and adolescents post-hospitalization?

Chi-square tests of independence will be calculated to determine if there is a difference in probability of the creation or revision of IEPs/504 plans across intervention groups. The Chi-square (χ^2) test will be used because grade retention is a dichotomous categorical variable. A Chi-square analysis will be run at each timepoint (baseline, 20 school days, 12 months). It will use a 3 (treatment group) by 2 (yes/no) table at each time point. If the chi-square test is significant, Cramer's V will be used to calculate effect size because the table is greater than a 2 x 2 table (Warner, 2013, p. 334). Post hoc analyses will consist of three 2 (two treatment groups) x 2 (yes/no) tables to determine the relationship between each two conditions. The results of the Chi-square test of independence at baseline are expected to indicate that there is no significant difference in probability of having an IEP/504 plan across treatment groups. The results of post hoc analyses at 20 school days and 12 months are expected to indicate that the probability of creating/revising an IEP/504 plan is significantly greater for the liaison group compared to the school presentations group or the treatment as usual group. It is expected that that the probability of creating/revising an IEP/504 plan will not differ for the school presentations group than the treatment as usual group.

Research Question 1c: To what extent does the type of hospital-based school re-entry program (treatment as usual, school presentations, and educational liaison) impact grade retention in chronically ill youth post-hospitalization?

A Chi-square test of independence will be calculated to determine if there is a difference in grade retention frequency across intervention groups. The Chi-square (χ^2) test will be used

because grade retention is a dichotomous categorical variable. It will be a 3 (treatment group) by 2 (yes/no) table. If the chi-square test is significant, Cramer's V will be used to calculate effect size because the table is greater than a 2 x 2 table (Warner, 2013, p. 334). Post hoc analyses will consist of three 2 (two treatment groups) x 2 (yes/no) tables to determine the relationship between each two conditions. The results of the chi-square test are expected to indicate that the probability of grade retention is significantly lower for individuals in the liaison group than the school presentations group or treatment as usual group and that the probability of grade retention is significantly lower for individuals in the school presentations group than the treatment as usual group.

Discussion

Summary

As students with chronic illnesses are able to return to school faster after hospitalizations due to medical advances, the development of evidence-based school re-entry programs to support their transition becomes more essential. This study aims to determine to what extent different school re-entry programs improve school outcomes, psychological functioning, and social competence in students with chronic illnesses. A randomized control trial of school re-entry programs within a children's hospital setting will be used to compare the effects of treatment as usual, presentations to peers and school staff, and educational liaison services on child outcomes in a sample of individuals with a variety of chronic illnesses. The anticipated results would indicate that educational liaison services result in the most significant increase in positive outcomes for school attendance, grade retention, IEPs/504 plans and psychological functioning. It is predicted that the school presentations intervention would result in the greatest increase in social competence because it intervenes directly with peers. These findings would suggest that school re-entry programs with either an educational liaison component or a school presentation component result in improved school outcomes for students with chronic illnesses. However, the educational liaison focused school re-entry program has a larger effect on more outcomes compared to school presentations.

These results would support the creation of educational liaison-based school re-entry programs for students who return to school after being hospitalized for their chronic illnesses. They would also indicate that the school presentation programs may be a less expensive intervention that results in improved parent ratings of child's social competence, higher self-

reported rating of psychological functioning, and less school absences than treatment as usual. These findings would also support the feasibility of school re-entry programs for children with chronic illnesses across diagnoses and age. Evidenced-based school re-entry programs, which are not age or diagnosis specific, are more applicable to the majority of medical settings. They also ensure more individuals have access to school re-entry services regardless of diagnostic label or specific inpatient service.

Limitations

A limitation of this study is the variability within research participants. This study accepts participants with any diagnosis of a chronic illness and there is significant variety in symptoms and the impact of different chronic illnesses. Although this decision was made to improve the ecological validity of the findings, it creates methodological complications. Due the heterogeneity of diagnoses, it is possible that these treatment effects are driven by individuals within a specific diagnostic category. It is also possible that treatment group effects differ by diagnosis. Certain treatments, such as presentations to peer and staff, may be optimal for specific diagnoses. The current study does not have the power to explore this possibility and more work is needed on diagnostic-related differences in school re-entry. The variability within the sample may also obscure potential treatment effects. However, the findings would still be important because they would suggest that a generic school re-entry program across diagnoses does not have a significant effect on child outcomes and diagnostic specific programs are necessary.

Another limitation is the lack of a universal standardized protocol for educational liaison intervention, which may hinder the replicability of this study. In the literature educational liaison re-entry programs have emphasized the importance of individualizing the intervention to each

patient (Arshad et al., 2015; Bruce et al., 2012; Prevatt et al., 2000). This preliminary study would establish the effectiveness of an educational liaison school re-entry program in a general children's hospital sample. Further interdisciplinary work will be needed to create a standardized protocol, which may be widely disseminated and applicable across diagnosis and medical setting.

This study will take place in a single children's hospital within a metropolitan city in Texas. The generalizability of these findings to other regions, population densities, and medical settings is unknown. This study must be replicated in other settings in order to determine if these findings are applicable to other populations and settings. The study is limited to the diagnoses included in the sample. It is a general sample of participants referred for a school re-entry program at DCMC. It does not include all chronic illnesses and may not be applicable to those populations. This study also only focused on individuals with chronic illnesses and the impact of these types of school re-entry programs on individuals' acute injuries post-hospitalization is unknown.

Finally, there is variability within the treatment as usual condition. Currently, there is no standard procedure at DCMC for the provision of school re-entry services at discharge. Treatment as usual can consist of setting up homebound services, general referrals to outside resources, or no services. This variety adds possible complications to the data. However, it is an accurate representation of the current school re-entry protocols followed as hospitals without defined school re-entry services. Therefore, significant differences between treatment as usual and the intervention conditions indicate improvements to current services.

Implications for Clinicians and Future Researchers

This study would determine the benefit of school re-entry liaison programs and school presentations within a general hospital setting. It also offers potential mechanism to address some of the psychological, social, and academic challenges that youth with chronic illnesses encounter after hospitalizations. Further work should be done on whether these programs' effects last beyond 12 months. Additionally, it would be important to assess if improvements due to these programs result in greater educational attainment long-term. Future research may also explore if changes in psychological functioning, social competence, school attendance, grade retention, and IEPs/504 plans are mediated by improvements in hospital-school communication. These findings would cement the importance of the incorporation of educational liaison services into medical settings.

This study would shed light on the different impact of school presentations and educational liaison services on the school re-entries of students with chronic illnesses. Research on a combination of these two interventions to create a more comprehensive program is also important in order to determine the school re-entry optimal procedure. A study of the benefits of school re-entry programs with both components compared to an educational liaison focused program would ensure that both components provide added benefits and that resources are not misspent.

This study would provide quantitative evidence for benefits of educational liaison school re-entry programs. Further work on which variables moderate the effects of school re-entry programs on transitions back to school would help enhance the design of school re-entry programs. It would be beneficial to consider the relation between school re-entry program outcomes and variables beyond diagnosis such as visibility of condition, degree of threat to life,

sensory or motor impact, and demanding/intrusiveness of care, which all impact psychosocial well-being in children with chronic illnesses (Barlow & Ellard, 2006). Additionally, since hospital-wide school re-entry programs serve students in elementary, middle, and high school, an exploration of whether school level affects school re-entry program outcomes also would be important.

Finally, future research should explore if parental or teacher factors are influenced by school re-entry programs. This study focused on child outcomes. However, it did not assess the potential impact of these programs on parents or teachers. Parent adjustment and coping after a child's diagnosis of a chronic illness relate to school functioning and involvement (Emerson et al., 2016; Suzuki & Kato, 2003). Further exploration of the program's impact on parental adjustment, coping, and stress could be an important area of future research. Additionally, both parents and children reported that teacher behaviors had an impact on school re-entry (Lum et al., 2017; Yi et al., 2016). A study of the effects of these programs on teacher behavior is another potential focus to consider for future research.

This study will provide an exciting first step in the development of evidence-based practices for school re-entry programs for children and adolescents with chronic illnesses. The study would demonstrate the potential of school re-entry programs to influence a variety of areas in which youth with chronic illnesses are at risk for negative outcomes. It would help to determine and establish the optimal method for school re-entry after hospitalization, which may have long-lasting effects on the academic, psychological, and social futures of children and adolescents with chronic illnesses.

Appendices

Appendix A

Case Example of Educational Liaison

Luisa, a 12-year-old girl, was admitted to DCMC due complications related to chronic kidney disease. She was hospitalized for three weeks and referred to the research study one week into her hospital stay by a member of her medical team. After completing the baseline measures, Luisa was randomized into the educational liaison intervention group. An educational liaison met with the family for an initial interview and identified the child and family's strengths, resources, and educational needs. Prior to her hospitalization Luisa had been a strong student who enjoyed school. However, she reported feeling worried that she had fallen behind in her classes due to her hospitalization and would be lost when she returned to school. Luisa's primary caregiver was her single mother, who had a close and loving relationship with Luisa. Luisa's mother described her concerns about sending her daughter back to school and wondered if homebound services would be a better option. She worried that the school would not follow Luisa's complex medical regimen. She also was concerned that Luisa would be exhausted by the demands of school, which would endanger her health.

The liaison facilitated a conversation about the case with Luisa's physician and her mother to determine if she would be physically able to return to school after she was discharged, the anticipated date of discharge, and what potential supports would be beneficial to accommodate Luisa's medical illness in a school setting. The group agreed that Luisa would be able to return to school in approximately two weeks but upon school re-entry she would benefit from breaks in the school day, access to a quiet place to lay down, access to her medications, and

an exemption from all physical activities. The liaison than called the school to discuss the families' concerns and the team's recommendations. The liaison collaborated with the school to set up a 504 plan, which ensured Luisa would have opportunities for breaks, a pass to visit the nurse's office to lay down, a specific plan for medication distribution with the school nurse, and an exemption from physical education. The liaison also discussed Luisa's concerns that she was falling behind in her classes and collaborated with the teacher to development a system for Luisa to access important school work while in the hospital, so she could continue to be a successful student after her hospitalization. After her three-week hospital stay, Luisa returned. Upon her school re-entry, the liaison continued to work with the family and the school to develop a system to monitor Luísa's academic performance and interactions with peers to prevent her chronic illnesses from further impacting her school experience.

Appendix B

Figure A. Study Procedures Flow Chart

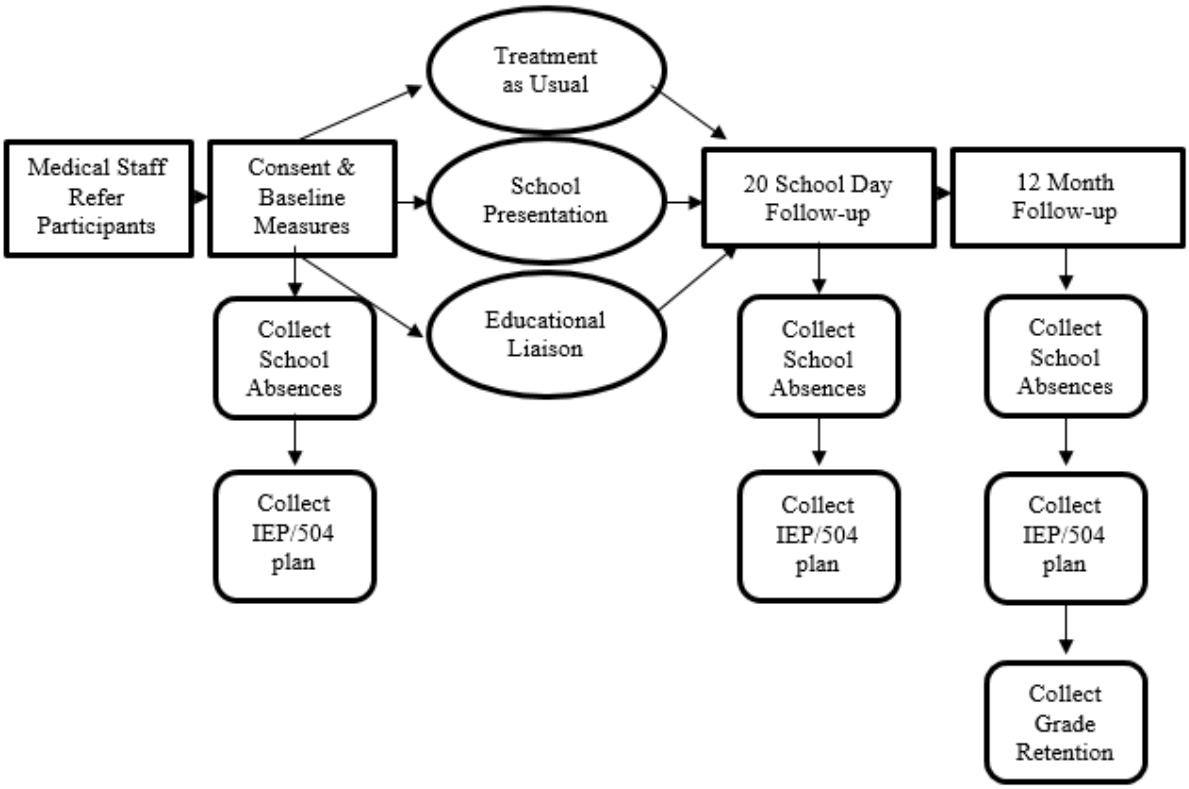
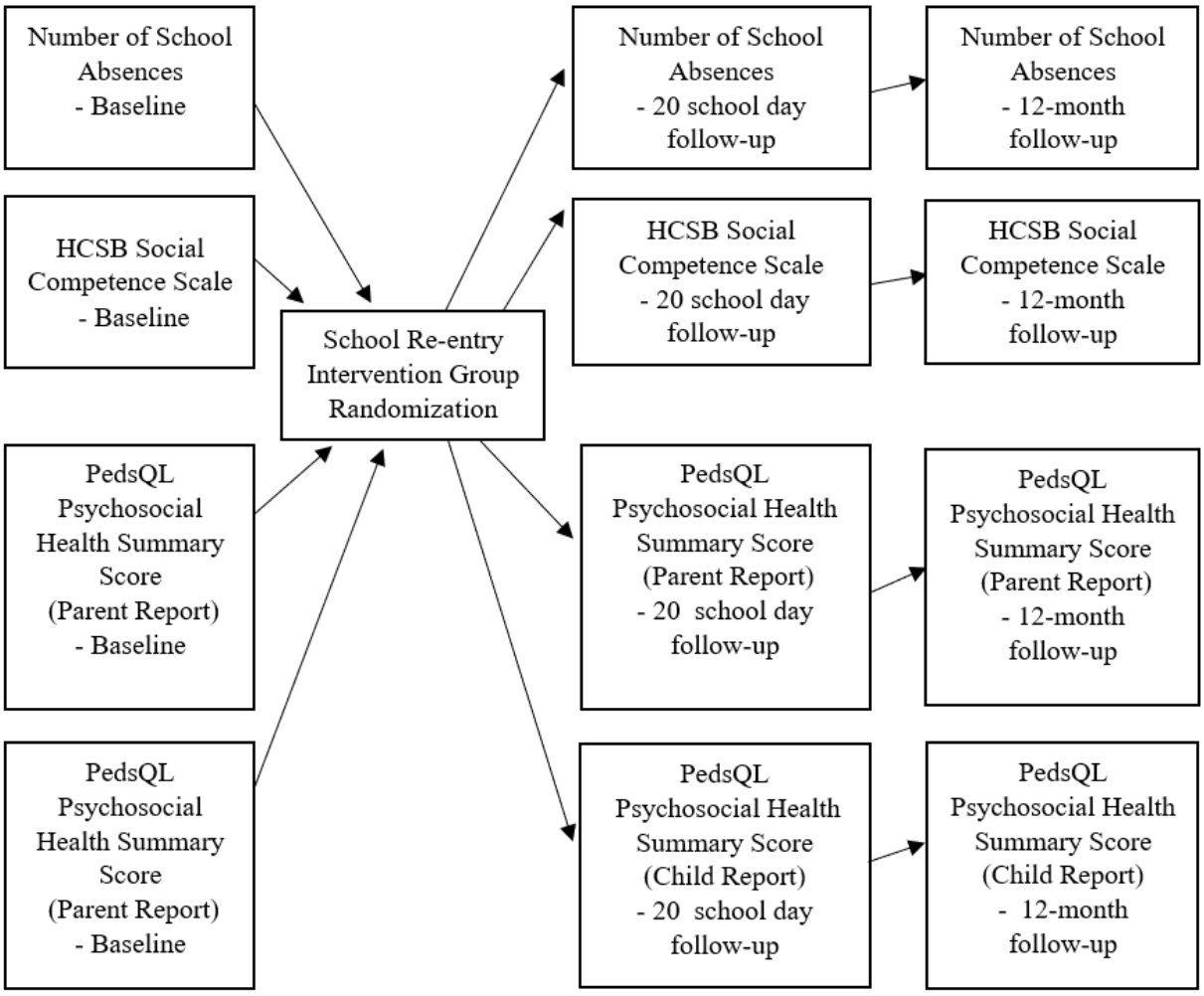


Figure B. Model of Repeated Measures MANOVA Model



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